Child Development Monitoring for Prevention of Disability

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Indonesia

Access to Health
We aim to **IMPROVE THE QUALITY OF LIFE OF CHILDREN WITH DISABILITY** focusing on underserved areas in Indonesia.

We serve children with disabilities. We provide **CLINICAL THERAPY** and **SPECIAL EDUCATION** to optimize children’s potential despite their limitation.¹

We serve mothers & health workers. We created **TOOLS** for monitoring child development to **DETECT DEVELOPMENTAL DELAYS** early and react accordingly.

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¹ Suryakanti foundation was established in 1984, and started to do child development monitoring in 1996
Source: Suryakanti Foundation
Early detection & intervention can reduce the severity of many conditions and help children adapt in life.

In rural areas, developmental screening is not part of routine examination, due to the lack of health professionals and large population.

Teach village health cadres and mothers to:
1) Monitor child development
2) Stimulate children with mild delay
3) Refer children with severe delay to health professional at earliest

Suryakanti leverages a simplified screening tool: CHILD DEVELOPMENT MONITORING CHART together with a stimulation manual.

Source: Suryakanti Foundation
WHAT IS OUR TOOL?
PICTORIAL DEVELOPMENTAL MILESTONE POSTER

APPLICATIONS

1. Home-based monitoring for early identification of child development delays to conduct immediate action

2. Epidemiological surveys

3. Assessment of school readiness

Developmental aspect
1. Gross motor
2. Fine motor
3. Perception
4. Speech/language
5. Social/emotional

Source: Suryakanti Foundation
EXAMPLES OF HOW TO USE THE TOOL

- **Suspect Autism** (Low perception, speech, social/emotional)
- **Suspect Cerebral Palsy** (Delay in almost all aspects, low social/emotional)
- **Suspect ADHD** (Very active, low speech, low social/emotional)
- **Suspect Down Syndrome** (Low motor, perception, speech)

Source: Suryakanti Foundation

*x-axis: Developmental aspect  y-axis: Age of child in months*

- Development as expected
- Atypical development
SURYAKANTI'S IMPACT MODEL

Social problem

Amongst others, the lack of knowledge on child development exposes children in underserved areas to higher risk of developmental delays & disability (also lack of access to services, poverty, nutrition, etc.)

Activities

Mainstreaming child development monitoring, early detection, and stimulation

A Adapt & provide easy to use child development monitoring tool
   # tools distributed

B Train health workers & preschool teachers to...
   • ...use the pictorial development monitoring tool
   • ...teach mothers how to monitor development, detect delays & give stimulation
   # trainings, # trainees, # mothers reached out to

Outcomes

I Health workers & teachers monitor child development
   # health workers implementing, # children monitored, # delays detected

II Mothers are aware of child development delay
   # mothers who monitor

III Mothers act early on development delay
   # mothers who stimulate

IV Health workers & teachers refer children with delays
   # referrals made, # children intervened

Ultimate goals

Decrease rate of development delays/ of children with disability through early detection, stimulation and referral to professionals where needed

Ultimate Impact measurement

Parameter

1. Home-based Pictorial Child Development Monitoring Chart and Development Stimulation manual
2. i.e. give stimulation for 3 months, then refer to health professionals if no progress
3. To be done with thorough research using baseline vs. achieved target state survey on intervention vs. control area

Source: Suryakanti Foundation
IMPACT OVER THE PAST 10 YEARS: SURYAKANTI SUCCESSFULLY REDUCES DELAY SEVERITY WITH TIMELY & PROPER INTERVENTION

<table>
<thead>
<tr>
<th>~7,000 TOOLKITS DISTRIBUTED&lt;sup&gt;1&lt;/sup&gt;</th>
<th>1,000+ TRAININGS CONDUCTED</th>
<th>3,600+ PEOPLE TRAINED</th>
<th>~80,000 MOTHERS &amp; CHILDREN REACHED&lt;sup&gt;2&lt;/sup&gt;</th>
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**URBAN EXAMPLE**

- Smart Steps Playgroup, Bandung
  - ~80 children monitored annually
  - 38% with atypical patterns in tool
  - 70% of those children received direct intervention along with stimulation at home

**RURAL EXAMPLE**

- Taman Posyandu, Sumedang
  - ~300 children monitored annually
  - 3.6% with atypical patterns in tool<sup>3</sup>
  - 100% of those children received stimulation at home
  - 10% ultimately referred to health professional for follow-up

**RESEARCH**

- Epidemiological Study 2008

Study demonstrates that pictorial developmental milestone tool can detect...

- ...28.6% of mild developmental delays
- ...8.9% of severe developmental delays

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1. The tool is included in the Ministry of Education National Technical Guideline for Early Childhood Development and produced & distributed independently by others outside Suryakanti. 2. Assuming 75% rate of health workers implementing tool with min. outreach of 30 mothers per year. 3. we believe this number is under-reported, several factors, among which different perception/ sensitivity, voluntary (in village taman posyandu) vs. compulsory (in smart steps playgroup) monitoring mechanism, and parents’ demand.

Source: Suryakanti Foundation
“At 4-years-old, our daughter Ragil was diagnosed by a midwife at a Suryakanti Clinic with severe speech delay. After a thorough test, she was diagnosed with Down Syndrome, speech delay and mental retardation. As her parents, we were broken hearted and in denial. We sent her to public school, but her behavior got worse. Not until she was 7 we returned to follow the clinic’s recommendation: speech and occupation therapy, and a special education school. At age 9 she learned how to swim as part of the therapy, and found her talent. In 2014, Ragil won a gold medal for the West Java team at the National Student Paralympics in Makassar. Now she’s a student in an inclusive school, while preparing to become a Paralympic national athlete. Despite her limitation, we are proud of her.”

Imagine, if we could help other 'Ragil's out there to shine
- Dr. Yulia, Suryakanti clinic
"As a health cadre and tutor in Taman Posyandu (village ECD center), I was first trained to do child monitoring in 2007. The training has sensitized me to spot delays among many children early.

For example, among our recent pupils, there is a 2.5-year-old girl who has speech delays and hence difficulties to interact with others. We conducted a home visit and explained the Suryakanti Child Monitoring Chart to the parents. We also asked them to actively pursue stimulation exercises, such as reading stories, talking more with the child, and providing toys for collective play. It’s not an overnight change, but the girl is progressing.”

“Every child entering Smart Steps Preschool is screened using Suryakanti’s Child Development Monitoring Tool in the beginning and every 3-6 months. If any developmental delays are detected, stimulation is given both at school, at home, and at a clinic if needed.

For example, one of our preschoolers, a 4-year-old boy was diagnosed to have delays in perception, language and socialization. We referred him to development clinic and he received 14 therapy sessions. He manage to catch up and was later declared as appropriate in all developmental aspects for his age.”

1. Developed with Frontiers for Health Foundation
Source: Suryakanti Foundation
CHALLENGES

1) Scaling: Raise funds & find partners for replication.

2) Impact measurement: Conduct large scale survey to further demonstrate impact

3) Marketing: Strengthen awareness of the program and Suryakanti’s brand, to attract philanthropy/donor.

4) Social marketing: Building awareness among the poor and near poor about disability prevention.

5) Research & Development: Improvement as well as building relevant new products/program.

Source: Suryakanti Foundation
Providing special education & tools as well as clinical therapy to prevent & respond to developmental delays with children